

## Statement of Senator Bob Dole

Mr. Chairman, Senator Breaux, and other members of the Committee, thank you for inviting me to testify regarding hospice care. I commend you for dedicating a hearing to this topic, which accounts for only about 2% of Medicare's total outlays, and especially to delve into the issue of access to Medicare hospice services. Indeed, the government must play a role in assuring appropriate access to Medicare services and I look forward to hearing from the other witnesses to gain their perspective on what more can be done.

My remarks will focus on the genesis of the hospice benefit and on those issues that I believe you may want to look more closely at to achieve improved access to hospice care for terminally ill Medicare beneficiaries.

The issue of end-of-life care has been important to me for many years. Nearly twenty years ago, I introduced legislation to establish the Medicare hospice benefit. The goal of hospice care, which was initiated in Great Britain, is to assist terminally ill patients in preserving as normal a life as possible, while remaining in their home, surrounded and cared for by their family. At the time, this was an unmet need of millions of Medicare beneficiaries and their families. As you know, the Medicare program initially centered on acute care and favored institutional care - mostly in the hospital. As a result, the Medicare program was focused, and mostly still is, on curative care. Yet, those facing death hope to die with dignity and once they come to terms with their diagnosis, their care needs shift from curative care to palliative care. Twenty years ago, people needed more than what was available to them in the Medicare program and hospice as uniquely qualified to deliver comprehensive care at the end of life. As a result of the addition of the hospice benefit; today, hospice provides the most significant care for Medicare beneficiaries who are terminally ill.

The hospice benefit was a unique addition to the fee-for-service Medicare program. It introduced a new choice specifically for terminally ill individuals. Hospice provided comprehensive care tailored to meet individual needs. It introduced flexibility to enhance the benefit package and provide homemaker services, counseling and prescription drugs, and it utilized a multi-speciality team of health care providers to assure a better quality of life for a terminally ill individual. Also, the hospice benefit embraced family life by supporting and educating a Medicare beneficiary's family to care for their family member in the home and by providing bereavement counseling to family members following death.

The hospice program has grown over the past 20 years to serve increasing numbers of Medicare beneficiaries. Throughout the first decade of the Medicare Hospice Benefit, hospices were slow to participate in the Medicare program. Luckily, today, most hospices serve Medicare patients and, in fact, Medicare patients represent two-thirds of hospice patients. This growth is good news. I urge you to remember that this is a relatively young benefit and the increase in patients and participating providers is most welcome. Also, these increases do not provide a comprehensive analysis regarding access to hospice services.

Inherent in a review of access to hospice, is the difficulty of assessing how many patients should be in hospice, but for whatever reasons are not. Nearly 2 million Medicare beneficiaries die each year. Yet, not all of them may be appropriate for hospice and not all of them may be comfortable foregoing curative therapy and accepting their impending death. For some, there may be cultural issues that discourage this care choice. When you think of access to hospice care, these are not the populations you worry about. Rather, it is those patients who can benefit from hospice care and who would elect the hospice benefit, but may not have enough knowledge of the benefit to make an informed choice, may not learn about hospice care from their physician, or may not have a hospice provider in their area. In

addition, access may be less than optimal for those individuals with complex medical problems, multiple diseases complicating care, greater social service needs due to impairments and higher cost medical needs. In other words, access issues in hospice do not easily reveal themselves. They are complex, involve perceptions, individual beliefs and an ability to accept death.

As you seek to improve access to hospice care, I urge you to review the current program with the goal to secure the future viability of the hospice benefit. Some areas you may wish to examine in particular include:

#### ELIGIBILITY -

There is merit in clarifying eligibility, specifically, that Congress never meant for the definition of terminally ill to serve as a barrier to access the benefit, but rather as a reasonable measure of when a person could be expected to come to terms with impending death. At the time the benefit was established, 6 months represented the general practice within the hospice industry. It was not a topic of debate, nor did we discuss how difficult this assessment would be for physicians. Although physicians are expected to certify that a patient's life expectancy is 6 months or less, by no means are they expected to be certain of that time-frame. Over the years, this issue has been revisited. HCFA revised its regulations ten years ago to clarify that the physician was only expected to base this judgment on the general knowledge of the course of the illness. In addition, Congress has revisited the issue and attempted to provide assurance by first revising, and then eliminating in 1997, the lifetime benefit limit of hospice. Bottom line, Medicare beneficiaries may live longer than 6 months and still be terminally ill and eligible for hospice. Unfortunately, the perceptions persist that this is a limited benefit and that it is fraudulent to refer a patient that may live longer. Ironically, this is the only benefit in the Medicare program to be frowned upon if it provides positive health outcomes, such as improved quality of life, ability to enjoy a day out of bed with the family, or stabilized health status.

#### DECREASING LENGTHS OF SERVICE -

As you review access to the Medicare Hospice Benefit, I urge you to consider the decreasing length of service indicative of late referrals. Last year, MedPAC wrote, "because of recent investigations by the Office of Inspector General examining long hospice stays, physicians may be reluctant to make six-month diagnosis in all but the clearest cases to avoid any perception of fraud. In such instances, "the patient may be admitted to the hospice either after hospice services may be of optimal value, or not all." I find the latter part of that statement very disturbing. Medicare beneficiaries may be accessing hospice, but they and their families are missing out on the benefit. This population of patients is choosing hospice and is eligible for hospice. Yet, I regret that many hospices report that patients are coming to them within days of death. Regardless of the reason for dramatic decreases in the length of service, it points to an access problem. Personally, I suspect there are a combination of reasons for the decreased length of service, including recent OIG activities, the need for improved discussion and education regarding this option, the physicians', especially those who may not refer many patients to hospice, uncertainty regarding the certification requirements or a misunderstanding of their role in a hospice environment.

Again, I greatly appreciate the opportunity to share my thoughts with you. We've come a long way in meeting the needs of terminally-ill Medicare patients. However, there is much to do to assure improved access. I hope that your continued attention to improve this benefit will result in a strong, viable hospice benefit for many years to come.